

# Disease Lobbies: Where, How of NIH Spending

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If code names have meaning, then a terrible thing has happened. American government, especially its gullible element on Capitol Hill, has been captured, bound and gagged by a silent invader.

Consider the names: the cancer mafia, the health syndicate, the benevolent plotters, the Laskerites, Mary's lambs, Mary's angels.

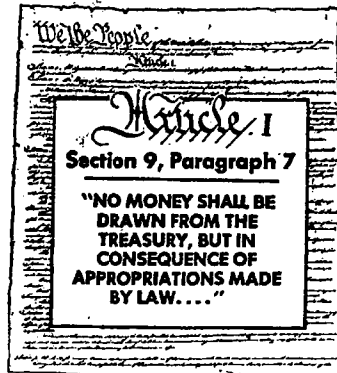
There are more. They are terms used to describe one of the most remarkably successful, yet least-known components of national politics—the public health lobby, or, as its various parts are sometimes wryly called, the disease lobbies.

Many of President Carter's budget proposals for public health spending in fiscal 1981, even though the president may not know it, are based on zealous evangelism of these groups.

One of the areas where this shows up most clearly is in Carter's proposal to spend \$3.6 billion on the biomedical research programs of the National Institutes of Health.

NIH and Carter administration officials have decided how much they would like to spend. Members of Congress and their staff assistants will decide how much NIH can spend. The public health lobby will play a key role in influencing *where* and *how* the money will be spent.

Long before Carter was president, the health lobby—a huge, shifting and hard-to-define army of citizens and or-



ganizations sworn to battle individual diseases—had made its imprint on official Washington.

Rep. William H. Natcher (D-Ky.), chairman of the House Appropriations subcommittee for Labor-HEW, put his finger on it at an NIH hearing the other day.

He looked down at Dr. Donald Fredrickson, director of NIH, and said, "Doctor, we will be approached by hundreds of advocates. How can we defend this budget?"

Fredrickson answered, "We will be able to fund good research in all of these areas. Their equity is protected. We need these people working upon us . . . We are a public body, and we hear from them, too."

As the congressional process works, the Senate and House Appropriations subcommittees, having heard NIH officials defend their budget in recent weeks, now are turning their ears toward public witnesses.

The first will appear Monday before Sen. Warren G. Magnuson's Senate panel. It will be almost like a factory. Principal groups are limited to less than 10 minutes each to try to influence the appropriation. Statements will be submitted for the record. Questions will be brief. The appearance of profound thinking may be coincidental.

In many ways, the process is too perfunctory and too overloaded to be meaningful. Legislators' time is lim-

ited, the witnesses who want to testify too numerous to accommodate, the causes and needs to be dealt with overwhelming.

The range of advocacy is huge.

It includes the powerful American Cancer Society, which would like to see the National Cancer Institute get more than the \$1,007,800,000 President Carter is proposing for fiscal 1981. Congress, with prompting by the anticancer lobby, has regularly increased NCI research money in the past.

And it includes smaller groups, for example, the enemies of Colley's anemia, a severe inherited blood disorder that principally affects person of Greek, Italian and Oriental ancestry. Congress, again with prompting, has pressed the National Heart, Lung and Blood Institute into research in that area.

Make no mistake about the influence of a group like the Colley's Anemia Foundation. Congress last year instructed the NHLBI to produce more public information about the disease. When Dr. Robert I. Levy, institute director, last week reported progress on that front, Rep. Silvio O. Conte (R-Mass.) was elated.

"All my Italian and Greek friends will be glad to hear that," Conte said. There was a ripple of chuckling in the subcommittee hearing room but Conte was touching the heart of the matter.

Esoteric investigation and dramatic discovery have made the 11 institutes of NIH what HEW Secretary Patricia Roberts Harris calls "the jewel of our national research crown." They exist for one reason: people like Conte's friends.

The multimillion-dollar budget arguments that occur each year when NIH goes before Congress always hinge on people. The difficulty is that there are many elusive diseases, many ailing people, many conflicting ideas about how to mount the war.

So politics is practiced. The disease that can be depicted as the most vile, the advocates who can capture the most legislative ears and individuals who leave the sharpest impressions win the appropriations battles.

The struggle for public health dollars has become so intense that part of the disease lobby, trying to hold down the chaos, has organized itself

This is another article in an occasional series following a single proposal—the budget for the National Institutes of Health—through the congressional appropriations process.

into the Coalition for Health Funding, 60 national organizations that watch the budget like hawks.

The coalition annually produces a complex and detailed alternative budget, typically recommending much more for public health spending than presidents propose. This year's alternative, for instance, calls on Congress to add \$330 million to Carter's NIH request.

In this year of general pressure for more budget cuts, the coalition's thinking seems unlikely to get very far. But it will have, as it usually does, an impact. "We think it provides Congress a mechanism to understand the programs we are interested in," said Jay B. Cutler of the American Psychiatric Association, who heads the coalition.

That, of course, is one way. But there are other ways—individual buttonholing of congressmen and the orchestration of ideas. Figures such as philanthropist Mary Lasker, columnist Ann Landers and actress Jennifer Jones, whose names are legend at the appropriations subcommittee, have converted that to a fine art.

Lasker is the spiritual godmother of

the sprawling disease lobbies, a friend of presidents' and senators and congressmen, who has spent the past 40 years promoting the idea of greater federal spending against disease.

The foundation created in her name and that of her late husband, advertising executive Albert Lasker, honors medical researchers for scientific advances. The Laskers have contributed heavily to the election campaigns of the congressional friends of health research.

Mrs. Lasker was a central player behind the surge of congressional spending on NIH during its "golden" years of the 1950s and 1960s. One disease after another got special attention, Congress earmarked money and new institutes were created as she made her persuasive rounds.

There is more to her style and her influence than Mrs. Lasker would like a listener to believe, but she makes an important point about political process and the way Congress appropriates money.

"Congress only responds to what it is told," she said last week. "It is very hard for people who are well and dynamic to imagine the plight of those who are ill."

"I feel very frustrated that I and others are not able to do more," she said. "But I'm just an individual citizen petitioner. That's all I am, but I do try. I would welcome more citizen petitioners. We have to go and see the congressional people and remind them of the needs."

Mary's Angels, they're called.